DOCUMENT RESUME

ED 325 999 EC 232 602

TITLE	Technology for People with Disabilities (Governor's Report and Executive Summary).
INSTITUTION	Minnesota Governor's Planning Council on Developmental Disabilities, St. Paul.
PUB DATE	Jun 86
NOTE	40p.
AVAILABLE FROM	Minnesota Governor's Planning Council on Developmental Disabilities, State Planning Agency, 300 Centennial Office Building, 658 Cedar St., St. Paul, MN 55155 (free).
PUB TYPE	Reports - Evaluative/Feasibility (142)
EDRS PRICE	MF01/PC02 Plus Postage.
DESCRIPTORS	*Assistive Devices (for Disabled); Compliance (Legal); Cost Effectiveness; Definitions; *Disabilities; Equipment; Financial Support; Incidence; Medical Services; *Needs Assessment; State Legislation; State Programs; State Surveys; *Technology
IDENTIFIERS	*Minnesota

ABSTRACT

This report summarizes the findings and recommendations of a Minnesota panel commissioned to find ways to: increase awareness of appropriate technology for persons with disabilities; provide access to appropriate technology-based products and services; and fund research and development in this field. The executive summary provides a definition of disability, incidence figures, and figures for costs to society of failing to help the disabled. Findings are reported in the areas of information dissemination, funding, and research and development. Findings include the following: (1) there is currently no systematic effort in Minnesota to gather information about existing technologies and their applications or to disseminate it; (2) there is no site where people with disabilities can have access to equipment for the purpose of assessing its potential applications; and (3) state agency definitions of such terms as "medical necessity" are unnecessarily restrictive and prevent or delay appropriate use of technology. Eleven recommendations include the establishment of an ongoing Advisory Board on Technology for People with Disabilities; provision of technology related training to professionals serving these people; and a requirement that public agencies and private insurance carriers expand their definition of medical necessity. (40 references) (DB)

****
* Reproductions supplied by EDRS are the best that can be made *
* from the original document. *
****

GOVERNOR'S REPORT ON TECHNOLOGY FOR PEOPLE WITH DISABILITIES

abilities

and technology

ED285809

U.S. DEPARTMENT OF EDUCATION

"PERMISSION TO REPRODUCE THIS MATERIAL HAS BEEN GRANTED BY

Coleen Wieck

TO THE EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)"

STATE OF MINNESOTA
JUNE, 1986

Introduction

In October 1985, Governor Rudy Perpich announced a 19-member *Issue Team on Technology for People with Disabilities* created to investigate the potential of high technology to improve the quality of life for Minnesotans with disabilities.

He said, "I am convinced that thousands of Minnesotans with disabilities could have their lives greatly improved by technologies which currently exist or by technologies which we have the capability of developing. It is our moral and economic responsibility to do all that we can to get it to them."

Over the next six months, the issue team explored ways to increase awareness for users, the public and professionals; to provide access to appropriate technology-based products and services, and to fund research and development that addressed the critical needs in the field.

This report is a summary of their findings and their recommendations for strategic action.

Battery operated arm capable of a 25 pound pinch.

Definitions, Causes and Incidence

NUMBER OF PEOPLE WITH DISABILITIES
BY POPULATION GROUP

GLOBAL: 400,000,000
US: 35,000,000
MINNESOTA: 600,000

The findings and recommendations of this report are based on two key terms defined as follows:

Disability — any condition that challenges the development or functioning of an individual, such as sensory, physical, mental, or emotional impairments; term is used interchangeably with "functional limitation."

Technology — the physical sciences and the processes of their application, including those devices designed to provide an assistive advantage for and by individuals, with the intent of eliminating, ameliorating, or compensating for one or more developmental or functional limitation.

Determining how many people are disabled is difficult. The range and degree of disabilities are complex. Data gathering techniques suit the definition of those who do the counting. The unpredictable nature of occurrence from birth defects, disease, accidents, and aging create an ongoing flux in the numbers. Cultures and environments have a role in determining whether people have functional limitations. And finally, rehabilitation and other enabling activity modify disabilities and change again the definition of limits within contemporary society.

By any measure, people with disabilities are a significant portion of the population. United Nations estimates claim 400 million people worldwide, or 10 percent of the total population. In the United States, estimates vary from 15 million to 45million Americans, depending on the severity of the disability. (Office of Technology Assessment, 1982, p. 21). The U.S. Census Bureau estimates that 35 million people have functional limitations. In Minnesota, a 1978 study estimated that 600,000 Minnesotans, or 14.5 percent of the population, were limited in one or more function of daily living (Inskip, 1986). Within the seven-county metropolitan area, there are an estimated 30,000 adults who are hard to employ due to physical and or mental handicaps. Sight, hearing , speech, physical mobility, emotional health, and ability to learn are all aspects of human capabilities subject to disabilities.

Findings

Technology has changed every facet of everyday life. During the past ten years, an explosion of technological wares has revolutionized the way we do things. To list the examples is to state the obvious. Opportunities for the inventive seem wide-open.

According to Hugh O'Neil in *Creating Opportunity* (1985), the single most important factor in determining overall productivity of the American economy in the years ahead is our ability to adjust to these technological changes. Our ability to compete with other industrial nations will be determined by the quality of our human resources. State governments in general will play a pivotal role in determining how effectively America nurtures its human resources.

Sue Warner, secretary. Public Relations, Sister Kenney Institute

"In a world where human beings and the machines they command have the power to control the quality of life, handicapping conditions can only be the result of a failure to properly apply technology or neglect of its development."

(Rahimi, 1981, p. 22)

According to a policy analysis report completed by Minnesota's Developmental Disabilities Council in April 1984, "Modern technology has been a major force in improving the quality of life for disabled persons. In programs throughout the United States, technological devices have been developed and adapted . . . in many activities [for people with disabilities]. However, the report goes on to say that "in spite of numerous innovative programs, resources, and expertise available in the area, many disabled people still do not have access to technology that could improve their quality of life" (p. 2).

The evidence suggests that while advanced technology is widely available in general, applications to the special, long-term needs of persons with disabilities is slow, sporadic, and uneven. Consider this irony—Alexander Graham Bell was working on a hearing aid for his deaf students when he developed the telephone. Consequently, the telephone became a mainstay of modern life and widened the gap between the hearing-impaired and the rest of the population. The typewriter, originally intended as a writing aid for persons with physical handicaps, ushered in the complex information-based society that threatens to intensify the differences between persons who are mentally disabled and the rest of society.

At the same time, technology's enormous capacity for variety, speed, specificity, and volume is suited to the complex circumstances of people with disabilities. Computers, initially developed for military uses, now enhance the mobility and communications of many persons with physical and sensory limitations.

Advances in miniaturization by the National Aeronautics and Space Administration (NASA) have led to the development of sensory biomonitors for people who are medically dependent (Winthrow, 1986, p. 65). An estimated 20,000 Americans now read, write, and speak through the use of specifically adapted personal computers (Sontag, 1985). People with visual impairment are assisted by a computerized synthesizer that reads messages aloud on a video screen.

Computerized keyboards and switches operated by an individual's hand, foot, head, or other body parts are making computers usable by those with limited mobility. Other devices include "laser" canes for persons who are vision-impaired, "electronic ears" for persons who are hearing-impaired, new developments in prostheses, wheelchairs, and an array of assistive apparatus.

Futurists envision even greater prospects. Writing in *Technology and Disability: Policy Issues in the Year 2005*, Clyde Behney (1986, p. 25), tells us that replacements or implants for eye lenses, the spinal cord, cochlea, brain tissue, teeth, skin, organs of smell, veins, arteries, and the nerve channels will be technologically feasible or markedly improved in less than 20 years.

In the short term, Behney says we will see some of these introduced in their first stages (p. 26). Prosthetics are expected to be far more sophisticated as advances are made in materials science, foreign body reaction control, miniaturization, bioengineering, and understanding of the dynamics of human movement, muscle, and nerve control.

Implantable artificial sensory aids will be under development or considerably improved over today's models, he says, while others (brain tissue, for example) are potential technologies whose fate will be determined in part by actions taken between now and the year 2005 (p. 27).

Currently, the high cost, lack of information, and limited research and development combine to keep pioneering efforts limited in their applications. At the same time, the population of persons with disabilities is increasing. Advances in neonatal care and chronic disease treatment, in particular, have resulted in an increase in the number of disabilities.

A dramatic example is the current prevalence of cerebral palsy in children. While the incidence of births of children with cerebral palsy has been reduced by one-half over the past ten years, a greater number of infants born with cerebral palsy are also surviving because of better treatment.

Without corresponding advances in the development and application of technology, their survival represents a growing strain on government for their life-long care and support.

In 1982, the Office of Technology Assessment (OTA) concluded in a report *Technology and Handicapped People* (1982), that "despite the existence of numerous, important problems relating to developing technologies, the more serious questions are social ones — of financing, of conflicting and ill-defined goals, of hesitancy over the demands of distributive justice, and of isolated and uncoordinated programs" (p. 14).

OTA also pointed out that "all decisions about the development and application of . . . technologies [for the disabled] are ones of resource allocation" (p. 13). However, this need not be interpreted to mean that each action incurs a direct cost.

The Costs To Society

The costs to society of failing to help persons with disabilities lead fully productive lives are high. According to national estimates, between 50 and 80 percent of working-age people with disabilities are unemployed. The result is that a significant portion of the population is unable to realize the American promise of life, liberty and the pursuit of happiness (Bradley, 1985, p. 1).

Among the estimated 15 million disabled persons of working age (16-64), the unemployment rate of 62 percent in later 1985 was up from 55.8 percent in 1978 (U.S. Department of Labor). The poverty level has also increased to 70 percent for families whose heads of households are disabled and earning less than $10,000 per year, as compared to 60 percent in 1975 (Bradley, 1985a).

According to Evan Kemp, executive director of Disability Rights Center in Washington, D.C., the resulting cost to society is $300 billion per year. Labor Department estimates show the annual societal cost for each of the 10 million unemployed disabled persons as $25,000 to $35,000 in lost wages, lost economic growth, food stamps, and medical payments, worker's compensation and unemployment insurance.

While technological devices and workplace adaptations can be very expensive, companies are finding that these costs are often far outweighed by the expense of long-term disability payments. "It makes good economic sense to accommodate workers rather than paying worker's compensation," says John Vaughan, a counselor at the Job Accommodation Network, sponsored by the President's Council on Employment of Handicapped in Washington, D.C. who advises companies on equipment that will be needed to hire workers with disabilities. (Bradley, 1985a).

In addition to savings in wages earned and lowered workers compensation and unemployment compensation rates, new technological developments can also bring about significant savings by helping prevent the occurrence of future disabling conditions; allowing people with disabilities to live in independent or semi-independent settings rather than in high-cost institutions; and providing the education and training necessary to enhance the employment prospects for persons with disabilities.

In Minneapolis, the Knox Lumber Company redesigned the workspace for Tom, a seven-year Knox employee who became a quadriplegic after a 1983 swimming accident (Johnson, C., 1983). Valued for his on-the-job skills, Tom was a worthwhile investment to his employer. "I am very fortunate to be in a position where they brought me back," Tom says, "I know a lot of handicapped people with really good qualifications who are not fortunate enough to have what I have."

The High Cost of Dependent Living

1985 PER DIEM COSTS FOR PLACEMENT:

FOSTER CARE: $12

SEMI-INDEPENDENT SERVICES: $24.82

COMMUNITY INTERMEDIATE CARE FACILITIES: $49.97

STATE HOSPITAL: $109.50

A cost comparison of institutionalized payment versus more independent living situations, often made possible through the use of special devices or services, demonstrates the high cost of the status quo.

Significant savings are indicated for foster care and semi-independent living. Technology can be an important influence on an individual's ability to function independently or remain in a hospital setting.

Judy provides a good example. Once hospitalized, she now lives in a one-bedroom apartment that is designed to accommodate her disabilities (Governor's Planning Council on Developmental Disabilities, 1984, March, p. 10). A network of friends and social service associates cooperate to ensure this living arrangement works for her.

Lake is another person whose disabilities were so severe that his doctor told the family he would be a "vegetable" for the remainder of his life and should be institutionalized (Kissick). Lake has progressed from using a simple head pointer and electric typewriter to using an electrical communication device and electric wheelchair. Lake lives in his own apartment and works as a salesperson for Prentke-Romich, Inc., the company that manufactures the communication device he uses.

Cost Savings through Prevention

Phenylketonuria (PKU) is a metabolic disorder that results in mental retardation without early detection and proper treatment. An effective PKU screening device is now being used at a cost of $2.50 per child (Minnesota Governor's Planning Council on Developmental Disabilities, 1984, March, p. 13). A PKU incidence of one person per 10,000 children tested means the cost of identifying a newborn with PKU is $25,000. Lifetime treatment for an untreated PKU child is in excess of $720,000. The savings to society, therefore, for each identified and treated PKU child exceeds $700,000.

Advances in prenatal screening offer similar hope for the early detection of genetic disabilities. Ultimately, researchers hope to detect prenatally a variety of disabilities and replace detrimental genes with normal ones, thereby preventing disabilities before birth.

The Benefits of Education and Training

Technology offers the opportunity to focus on abilities, rather than disabilities, of people with functional limitations. Technology stimulates and encourages individuals to tap inner resources. Developing alternative styles and uses of technology based devices are possible when an individual is given access. Overcoming functional limitations with technology could eliminate or at least reduce the need for "rehabilitation" as we know it (Office of Technology Assessment, 1982, p. 13).

"It is far more expensive to continue handicapping America than it would be to begin rehabilitating America. Keeping disabled people in dependency is costing us many times more than would helping them to independence."

(Frank Bowe, Office of Technology Assessment, 1982, p.1)

For many, assistive devices or technology related services make possible employment, independent living and participation in everyday affairs of the community. Several efforts are already underway to tap the job potential of Minnesotans with disabilities. A federal grant of $500,000 annually for a five year period offers people with severe disabilities new opportunities to work at community job sites.

The Office of Transition, funded by the 1985 legislature within the state Department of Education, is working to ease the transition from school to work settings for teenagers who are disabled. Other transitional programs are being offered through the joint efforts of the Division of Rehabilitation Services in the Department of Jobs and Training and Centers for Independent Living in the Twin Cities, Rochester and Marshall. These programs are small, though important, steps towards providing needed services to others seeking employment.

A case in point is the Maine Rehabilitation Project in Data Processing. This prototype demonstration project links business, education and state government in addressing social, psychological and economic needs of program participants. Since 1978, the project has provided training for business application computer programmers. Greater collaboration has resulted between the private and public agencies. Participants report increased sensitivity to their needs. Operational expenses are covered by a 200 percent rate of return (White and Cormeier, 1986).

Closer to home, the Division of Rehabilitation Services (DRS) in Minnesota's Department of Jobs and Training estimates a 34.8 percent rate of return on the investment made to provide vocational rehabilitation in the state. DRS figures show that their clients are able to increase earnings by $11.44 for every vocational rehabilitation dollar spent. That's $3.32 for each dollar spent and an estimated net profit of over $38 million.

With the increasing role of technology in the workplace and the demonstrated ability of people to compensate for limitations with new skills, continued success employing people with disabilities seems assured.

Vu, a client of the Cerebral Palsy Center using a Able-Net Stander and single switch.

Education and training will increasingly hold the key to the future employment of persons with disabilities in another way as well. Estimates are that by 1990 there may be eight keyboards for every ten employees in many company offices (Honeywell, internal study, 1985). Some technologies are replacing whole job categories, as word processors render some secretarial functions unnecessary, data bases replace file clerks, and source data collection eliminates the need for keypunch operators.

Adequate, broad-based training in skills necessary for a technology driven workplace will make available the employment opportunities people with disabilities need. Since he was three years old, Dan has experienced progressive physical and mental deterioration as a result of Huntington's Disease. He has used a computer with the assistance of his school's Automated Learning Device (ALD) Project team to enable him to continue learning (Ablenet, 1985).

Meanwhile, at Boston's English High School, a 20-year-old student, Louis, communicates via computerized voice synthesizer (Bradley, 1985c, p. 7). During his first six months with the computer, he built a non-existent vocabulary to the level of junior high school student.

These stories illustrate how people have seized the technology available to work at finding their abilities and skills. Dan, Louis and thousands of others need only the access to available technologies. In short, the Office of Technology Assessment report (1982) says, "an increased concentration on abilities could lead to the expenditure of a greater portion of resources to alter aspects of the environment that turn disabilities into handicaps" (p. 13).

Conclusions and Recommendations

A significant gap exists between the possibilities offered by technological devices and the realities of their applications. Some restrictions are purely monetary, resulting from the high cost of matching devices with disabilities. Others result from a lack of adequate, available information about appropriate technology for users, the public and professionals. Still others result from gaps in the process of research and development, that broad area of activity in which needs are identified and products/services are developed to fill the need. All three of these areas must be addressed if disabled Minnesotans are going to be able to fully avail themselves of and benefit from appropriate uses of technology.

Wheelchair accessible kitchen at Sister Kenney Institute.

Information Dissemination

A STRATEGY:

TECHNOLOGY INFORMATION PROVIDERS

AWARENESS

TRAINING FOR PROFESSIONALS

IMPLEMENTATION FOR CONSUMERS

A great need exists in Minnesota to distribute useful information on technologies. No systematic effort is being made to gather information about products or services and their applications. People with disabilities and medical professionals do not have a centralized location to assess potential use of assistive devices. No centralized resource center offers state-of-the-art training or information for professionals.

The following sequence of information activities is suggested in order that maximum benefits from existing products and services are obtained:

1) **Collection** — systematically gather information on existing technologies and their applications
2) **Distribution** — disseminate information to consumers,
3) **Practical application** — provide hands-on opportunities to view and experiment with a variety of assistive devices in the privacy of an individual's home or an office space.
4) **Training** — inform professionals so that they can offer assistance in selecting appropriate devices for individual needs.

Such a strategy helps individuals like Sandy, a severely disabled woman who is active in her community, works and lives alone. The one barrier she has not overcome is her speech disability. A talking board or a synthesizer does not meet her need or minimize her difficulty. Sandy would like a device that would not be cumbersome, but she has been unable to find anything. She is at a loss for suggestions on where to go next. With an information source, Sandy could continue her search and likely find a solution.

Funding

Lack of funding is a persistent and underlying problem of accessibility to technology for people with disabilities. Purchase and maintenance of assistive devices and for support services is often too expensive. Financing for devices and services which relate to mobility, communication and control of a person's environment is an essential prerequisite for their use.

In most cases, the technology exists, but access to it is severely restricted by the economic status of many people with disabilities and by constraints that remain in our current funding systems, both public and private.

Public Funding. It is obvious that some public funding guidelines and rules are essential, particularly in light of the number of people with disabilities who depend on public programs to meet their needs. However, too often these needs remain unmet because of barriers that result from outdated definitions of terms, rules drawn arbitrarily tight to forestall challenge (and hence change) and minimize expenditure, and prior authorization procedures which are expensive, self-contradictory and discourage technological advance.

"Currently, only a fraction of disabled Americans are able to benefit from existing technologies that would improve the quality of their lives. A national commitment is needed to assure that all disabled Americans, regardless of the nature of their disabilities or their financial status, can secure, and utilize any proven technologies that will enable them to lead more productive, functional and satisfying lives."

(LaRocca and Turem, 1978)

It may be useful to begin with some background information about public funding in Minnesota. The Medicaid or Medical Assistance (MA) program is a federal-state, income-tested program which provides medical and health care benefits to low-income elderly, blind, and disabled individuals and to low-income families with children. Although Title XIX of the Social Security Act created a single program of medical assistance with some national standards of eligibility and services, the states retain considerable discretion with regard to who is served, the scope of services provided and the amount and duration of those services.

In Minnesota, several state administrative rules exist which govern the operation of the Medical Assistance program administered by the Department of Human Services. The rule focusing on eligibility and services is Rule 47. Currently that rule is going through final stages of review and modification. The statement of need and reasonableness for the services section is currently being drafted and a hearing on this portion of the rule is anticipated during the summer of 1986.

Presently, many services and equipment under the Medical Assistance program require prior authorization by the Department of Human Services (DHS). A high proportion of medical supplies and durable medical equipment, including prosthetic and orthotic items, require this prior authorization and some are routinely denied under MA through the prior authorization process.

Two critical concepts and their interpretation by the Department of Human Services have served as a basis for approving or denying various types of equipment and devices: 1) the accepted community standard of medical practice and 2) the need for the service to serve a medical purpose for the recipient.

Both concepts are part of Minnesota's current operational definition of medical necessity and were originally implemented to eliminate purchases of equipment which did not provide a real benefit for an authentic medical purpose. The concepts have also been used, however, in a way which prevents some very significant categories of rehabilitative equipment (e.g. augmentative communication equipment) from qualifying for payment by supporting the contention that those categories do not serve a medical need in spite of the fact that they serve a rehabilitative need.

The working definition of medical necessity used by the State of Minnesota to approve/deny payment for technological equipment and services must be revised. This problem was addressed at the national level by the Congressional Office of Technology Assessment (OTA), which found that people with disabilities ". . . are often denied payment for technologies that are not considered strictly medical in nature, although the technologies would improve the ability of the individuals involved to lead more independent, productive lives. The current patterns of reimbursement exist largely because of the history of these programs as assistance for acute medical problems rather than for the chronic problems faced by the disabled" (1982, p. 178). OTA concluded that, "A significant effect of the current system is that in the short term, funds may be saved, while in the long term, a greater amount of total funds is expended" (p. 179).

The problem is clearly that the working definition of medical necessity used by the State of Minnesota (and many other states) relates to acute, dynamic health impairment and not to chronic health impairment. The term medical necessity, when applied to the care of people with chronic impairments, must address independent functioning. Removing obstacles to functional independence is a medical necessity.

Regarding children, medical care to foster long term independent functioning must address child development issues and opportunities or it is not valid. A child's ability to acquire cognitive, social, and motor skills, particularly in the critical years from birth to two, is dependent on interaction between the child and his/her environment. For children with disabilities, achievement of critical early developmental tasks is stymied by restrictions on exploration. They must have assistance from rehabilitative technology to enable personal interaction and environmental master. Removing obstacles to child development is a medical necessity and is the only road to maximum, functional independence in adulthood.

One final point related to the proposed Rule 47 definition of medical necessity needs to be addressed. While the notion of restoring an achievable level of physical or mental function is included, the concept of maintaining or slowing deterioration of existing physical and mental functions is not presently incorporated into the definition. Given the nature of many chronic conditions, such a limited focus does not address the long-term care needs of a portion of the Medicaid population.

The second key term which needs redefinition is that of "prevailing community standard" (PCS). Prevailing community standard (or standard of community practice) is a concept that is included in the rules to ensure that public monies are not spent for equipment unlikely to give significant benefit and acceptable value. Unfortunately, it has become operationalized as a rationale to deny payment for equipment that, for some patients, is clearly capable of minimizing the

adverse effects of illness, injury, or other impairments but has not, for whatever reason, been covered in the past. Once a category of equipment is denied PCS status by DHS or Blue Cross/Blue Shield, each denial adds evidence for the next. What is needed is a way to allow well-considered advances timely passage into PCS status while blocking adventurous, casual, or needlessly expensive prescriptions. The key to this problem is untangling the two concepts and applying them sequentially.

Another key funding issue which must be addressed is prior authorization, the procedure by which payment decisions are made. Currently, payment for equipment through the Department of Human Services is handled in one of two ways. When equipment fits one of the specific descriptions in an approved list of coded items and when its price falls under a DHS-specified dollar level, payment is made with minimal encumbering documentation and review procedures.

If the item description or charge does not fall within the code scheme or dollar level respectively, the prior authorization (PA) procedure must be followed. It should be noted that the dollar level is not item/code specific, but is applied to broad categories. The dollar level has been so low, for instance that virtually every prosthesis must go through prior authorization even though most have been assigned code numbers.

The rationale for setting up the payment system in this way is obvious. However, the PA procedure contains some very serious problems and inconsistencies. First, the requirement that authorization be obtained prior to provision causes needless delay that is particularly harmful to growing children and necessitates additional travel that is especially expensive for families living outside the metropolitan area.

Second, applications of recent advances in technology and design routinely incur the penalty of the higher level of documentation and review procedures, not just the first few times, but every time, until codes are favorably changed. Technological advancement is, in effect, discouraged by both the delay and the additional costs incurred in meeting PA procedure requirements. The number of payments that fall under the prior authorization process must be reduced and, in some cases, alternate procedures must be adopted in order to reduce the costs and frustrations of the present system, thereby getting technology more quickly and effectively into the hands of those who need them.

Finally, public funding requirements must recognize the importance of rehabilitation engineering for conducting assessments needed to select equipment that is most appropriate for individuals and providing the training needed to ensure the full, proper and safe use of that equipment. Most people with disabilities have individual needs which, if examined closely are unique. Which piece of equipment among various possibilities is most appropriate or what components must be combined to create effective systems cannot be determined without evaluation.

Training must often be given to the recipient and to others in his/her environment to ensure that equipment is fully, properly and safely utilized. The greater the sophistication of new devices, the greater is the role and importance of technological (rehabilitation engineering) services. A system which pays for the purchase of complex equipment but does not provide technical evaluative system design and training services is very like a health service which invites patients to come into a well-equipped dental office to fill their own teeth.

In a report to Congress, the Office of Technology Assessment stated that "reimbursement for an expanded variety of technologies should not be pursued without accompanying reimbursement for the services of those who select the technologies, those who fit them, and those who train the users in their proper use." The Minnesota Department of Human Services (DHS) currently recognizes the legitimacy of rehabilitation engineering charges only from designated rehabiliation facilities. However, the majority of technological equipment is prescribed and/or provided by institutions which cannot qualify as rehabilitative facilities.

The latest draft in the process of revising DHS Rule 47 does not address rehabilitation engineering services, a rather embarrassing fact for a state which claims to be at the forefront of medical technology development. It is also a very wasteful policy resulting in inadequate evaluation of needs, inappropriate training, and sophisticated equipment that sits unused in closets.

Addressing these public funding problems will, in the long term, produce economies for society by directly promoting healthier, more functional and more independent lives, and in some cases will help effect immediate efficiencies. However, a change in the laws and rules of a program such as this might increase short-term spending levels. Therefore, a mechanism will be needed to ensure that the cost is not excessive.

Private Insurers (Health Maintenance Organizations). Although many families with children and adults who have disabilities are covered by Rule 47, the majority utilize private carriers and HMOs through their employers. The problems cited earlier relative to public funding also exist in the realm of private insurance funding, but to an even greater extent. Working definitions of medical necessity are very restrictive and variable. Covered technologies are sometimes extremely limited. Investigative technology is not funded, nor are computers and augmentative communication devices. In order to receive needed equipment, a lengthy appeals process must often be followed.

When the State of Minnesota determined that its citizens were not adequately served and protected by the variable and arbitrary coverage given by auto insurance policies, legislation was enacted to ensure minimal levels of policy coverage. The needs of people with disabilities are no less important. Broadened definitions of medical necessity utilized by private insurance carriers would help remove functional obstacles from the lives of people with disabilities by helping them secure needed technologies.

"The years ahead can be years of advancement or of retreat, a breakthrough of new ideas or an attempt to keep a questionable status quo. The challenge to improve belongs to all of us."

(Governor's Planning Council on Developmental Disabilities. (1983, January). Developmental Disabilities and Public Policy: A Review for Policymakers).

Other funding options. We have seen that the development and implementation of new programs and services for persons with disabilities is largely contingent upon the availability of funding. Given the fiscal constraints presently facing all levels of government and the resulting high demand for limited private resources, it is unlikely that such funding will be readily available, at least in the forseeable future. However, limited funds can be freed up and their effectiveness maximized when a means is provided to use a combination of public and private sector funds, tapping one source to leverage the other.

The precedent for this sort of joint funding has already been established. One example is a $5 million award from the William L. McKnight Foundation to Hennepin County for the development of community-based mental health programming from 1981-1985. The grant agreement stipulated that Hennepin County match each dollar of the McKnight award with two county or state tax dollars. As a result, the county was able to undertake a major effort which may not have been possible had it been forced to rely on funding from a single source. Several pieces of recent state legislation have required similar private matches before the release of state funds.

Several other crucial issues must also be addressed. First, a better means of providing needed equipment to people with disabilities is needed. Pennsylvania's Assistive Device Loan Program provides a model for a mechanism to provide individuals with technologies appropriate to their needs, both within an individual's environment, training in the uses and applications of devices, and upgrading and recycling of equipment as needs change are key elements of Pennsylvania's program and should be part of any effort modeled after it.

Second, coverage is needed for persons leaving employment as a result of disability. Presently these persons have a 29-month waiting period before federal disability insurance coverage begins. The Office of Technology Assessment has suggested that Medical coverage be extended to cover this time period. Another option would be to develop incentives for employers for an additional 12-29 months following termination due to disability.

Finally, even for a family with good insurance coverage, the chronic disability of a parent or child can result in an immense long-term financial burden. They need assistance or encouragement to continue their struggle to maintain financial independence.

Research and Development

Research and Development (R & D) addresses a wide array of types and severities of disabling conditions. Specialized technologies currently being used or needing to be developed range from $3 specialized forks and spoons to $25,000 computerized reading machines for people who are blind. System technologies are those that make transportation and buildings accessible. Service technologies (e.g. rehabilitation therapy) combined with devices, encompasses the full range of technological applications to be considered.

The federal government has a clear role in carrying out and/or supporting disability-related R & D. This includes funding for specialized research, estimated at $40-$50 million annually, and the funding of general research by the National Institutes of Health, much of which impacts on persons with disabilities.

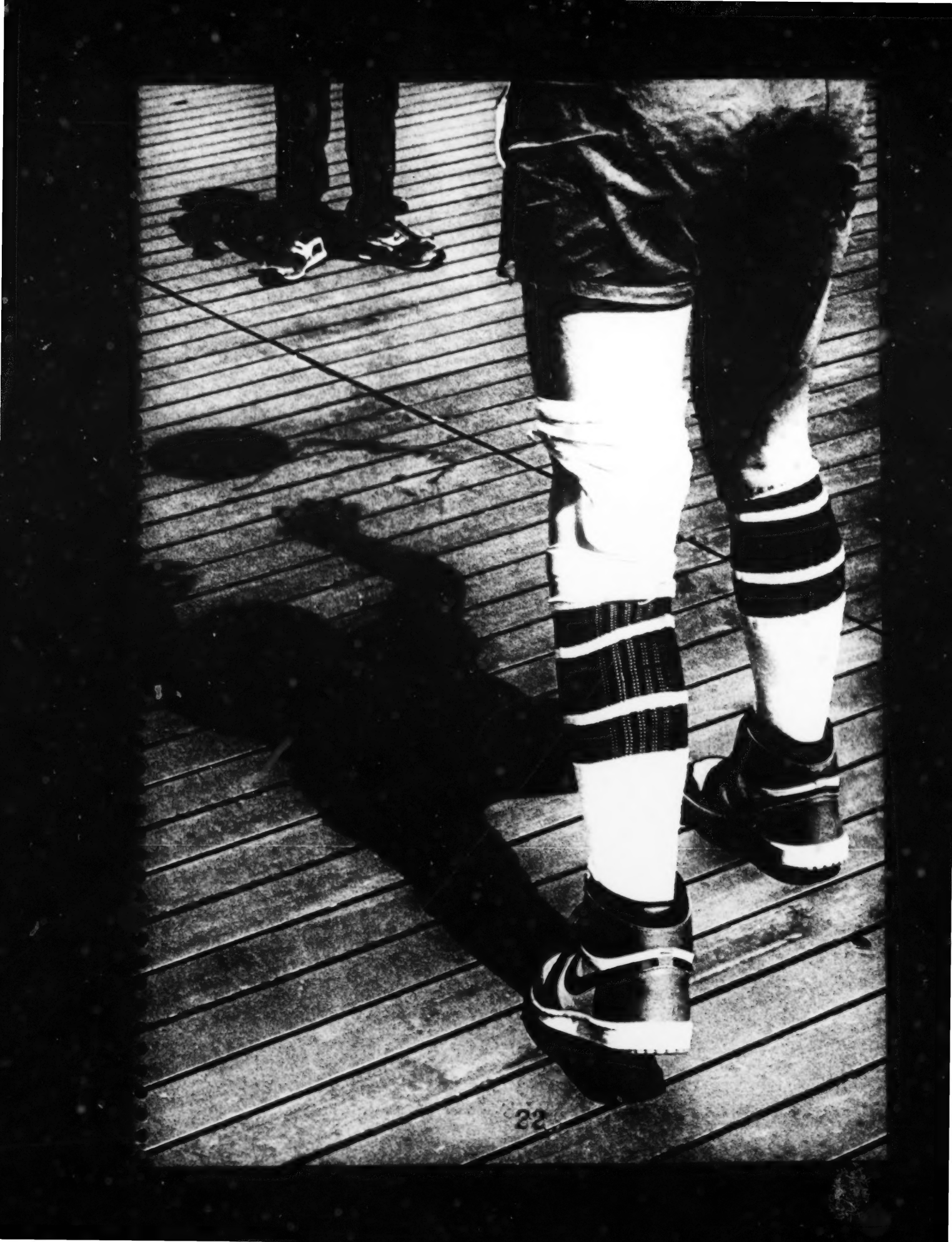
By any estimates, however, the level of federal funding for disability-related research is very small in comparison with total health care expenditures, health care research efforts and the amount of funding for transfer programs for the person with disabilities. Because the federal government assumes the responsibility for approximately 66 percent of all health research conducted in the United States, it has become the driving force in setting research priorities for health care in general and therefore for disability-related research as well (Office of Technology Assessment, 1982, pp. 59-60).

The National Institute for Handicapped Research is the primary federal entity responsible for disability-related research. Its research goals are met through the work of rehabilitation research and training centers (RTCs), rehabilitation engineering centers (RECs), spinal cord injury rehabilitation centers, centers for deaf-blind youths, and coordination with the international rehabilitation research centers. Its general research functions and priorities are set by the National Council on the Handicapped.

Other federal agencies which are involved in disability-related research include the Veterans Administration, the National Aeronautics and Space Administration (NASA) and the National Science Foundation (NSF) as well as, to a lesser extent, the departments of Transportation, Defense, Labor and Commerce, the Federal Drug Administration, the Social Security Administration, the Health Care Financing Administration, and the National Bureau of Statistics (Office of Technology Assessment, 1982, pp. 60-68).

While these federal efforts are vital for setting national research priorities and directing federal dollars toward the needs of persons with disabilities, the distance of the federal government from consumers and the severe funding limitations imposed in recent years on federal programs limit the effectiveness of efforts at this level.

Jess Meuller trying out his new state-of-the-art Flex Foot that was fashioned for him at the Gillette Hospital, St. Paul.



In many ways, the states have traditionally met the educational and occupational needs of citizens and can more appropriately address the needs of the person with disabilities and the ways in which technologies can help meet them. However, insufficient identification and prioritization of needs, a lack of coordination of public and private sector efforts, and a paucity of attention to R & D have precluded the kinds of results required to adequately address the ways in which technology enhances the ability of people with functional limitations to overcome many of the barriers imposed by their condition.

In general, three activities must take place in order for effective R & D to occur:

1) **Identification and Documentation of Needs and Existing Technologies.**
   A first essential step is to identify the needs of the person with disabilities that are either unmet or inadequately met. A catalogue of existing technologies that might be used or adapted to meet such needs should be established. Gathering both kinds of information avoids costly duplication of existing but unknown or under-utilized technologies. Companies will become fully aware of the limitations of particular disabilities and identify technology needs whose solutions are nonexistent. This task will never be complete, however, a consistent effort by a coalition of consumers, producers, advocates and professionals could bring about progress to this end.
2) **Development of a mechanism to disseminate this information to producers and consumers and to encourage on-going dialogue between them.**
   The most vital link in the three-part R & D chain is the middle one — the process of disseminating information once it is gathered. If companies and individual entrepreneurs interested in developing or adapting technologies for people with disabilities, they must be fully aware of the nature and extent of such needs. At the same time, where existing technologies are not adequately meeting the needs they were developed to meet, modifications will not be made if no means is available for on-going dialogue between consumers and developers to discuss such problems. In order for this vital communication to take place, a mechanism must be developed and an individual group, or entity must be charged with the responsibility of implementing it.

3) Incentives to Encourage the Development and/or Transfer of Technologies and Technology Uses.

The research and development of technologies applicable to persons with disabilities must be encouraged and supported throughout a continuum from basic research, designed to advance basic scientific knowledge, to applied research, the stage at which prototype products or processes are developed, to applied clinical research, the point at which problem or person-specific development takes place.

Traditionally, the federal government has assumed the primary responsibility for supporting basic research, usually conducted in universities and national laboratories. State government has most often been active at the applied research stage, supporting practical applications of research results in educational and industrial settings. Applied clinical research most often takes place in hospital and rehabilitation settings and has been the responsibility of both the private and public sectors.

The institutions where research is currently being carried out need to be recognized and supported. Other institutions need to be encouraged to join their ranks, building on their own unique strengths. Work such as that is taking place at the University of Minnesota. The implementation of functional electrical stimulation and the investigation of basic human communications which influence the design of augmentative communication products (e.g. a voice synthesizer) must continue. At the same time, the transfer of technology to produce devices for people with disabilities must also be encouraged.

Unfortunately, new product development is often expensive and carries with it the risks that must be assumed when developing products for an often ill-defined marketplace. Technology transfer can also be expensive because of the difficulties of extracting a technology for a new application and/or dealing with proprietary restrictions. Both are essential, however, in order to maximize the ability of citizens with disabilities to become self-sufficient, productive members of society.

None of these three activities can be overlooked if a means by which technology can help overcome the limits imposed by a range of disabling conditions is to be provided.

21

Recommendations

Technology offers means to compensate for limitations posed by a variety of disabilities. Carefully guided action will ensure that appropriate devices and services become available. In its report, *Toward a Developmental Disabilities Policy Agenda: Assuring Futures of Quality*, the Governor's Planning Council on Developmental Disabilities (1984, March) outlined five action steps toward the goal of providing access to technology for all persons with developmental disabilities:

- **develop and implement a state policy agenda for the use of technology by people with disabilities in Minnesota**
- **increase awareness of technological advancements among persons with disabilities and their families, professionals, policymakers and the general public;**
- **train professionals from a range of disciplines on the uses of technology for persons with disabilities;**
- **provide access to adequate assessment, prescription and follow-up services for individuals with disabilities who need technological aids; and**
- **modify funding mechanisms to allow the purchase and maintenance of technological aids and related support services (p.44).**

The Issue Team on Technology for People with Disabilities fully concurs with the findings of the Council on Developmental Disabilities, which apply to persons with functional limitations as well. The following recommendations provide the means to achieve these goals which, given sufficient funding and staff support, could be implemented with a two/three-year time period.

1. An on-going Advisory Board on Technology for People with Disabilities should be established as a successor to the Issue Team on Technology for People with Disabilities. The Board would carry forward its work and implement its recommendations. The Board would have a full-time staff and its members, appointed by the Governor, should reflect a breadth of competence.
   - **a.** Members should include representatives of the private sector, service agencies, consumers, third party payers, education, and library systems.
   - **b.** Ex-officio members should represent the Council on Biotechnology, the Department of Education, the Department of Human Services, the Division of Rehabilitation Services, (Department of Jobs and Training), the Governor's Office of Science and Technology (Department of Energy and Economic Development), State Council for the Handicapped, and the Governor's Planning Council on Developmental Disabilities (State Planning Agency).

Finishing touches on extension prosthesis, Gillette Hospital

2. A mechanism should be established to gather information on existing technology for persons with disabilities and disseminate through a central collection site (e.g. the State Council for the Handicapped) via a toll-free number.
   a. A survey to gather information should be conducted including Minnesota-based technology providers (private entities, education programs, and rehabilitation organizations and services) and print/video/electronic resources that exist.
   b. A database should be developed from the survey to make the information available. This database could resemble the Abledata study design, but will require very specific information in order to narrow the resource/solution possibilities.
   c. Guides that show consumers and producers of technological devices how to use/adapt/access technology products should be developed.
   d. A network should be built between the central site and local communities to make information, providers and trainers available throughout the state. Libraries in particular could serve as a vital part of this network, which could take advantage of the libraries' regional locations and their resources.

3. A statewide media campaign should be develped to heighten the awareness of the general public of available technology-based products and services and their implications for persons with disabilities.

4. A sequential strategy should be developed to provide technology-related training to professionals in special education, rehabilitation, county case management, and other areas of care-giving, as well as families, utilizing regional workshops and independent study modules to make the training easily and widely accessible.

5. Public agencies, private insurance carriers, and Health Maintenance Organizations (HMOs) should be required to expand their definitions of medical necessity, revise their definitions of prevailing community standard, and provide extended disability insurance coverage.
   a. Appropriate state agencies should be directed to modify their definition of medical necessity to address functional independence, child development, and the amelioration of slowed deterioration of physical or mental function, with these changes included in the revised Rule 47 of the Department of Human Services.
   b. Legislation should be passed requiring that private carriers broaden their definition of medical necessity and extend coverage to include technologies necessary to remove functional obstacles from the lives of people with disabilities.

c. In line with a definition of medical necessity that relates to the existence and extent of a generic medical need, prevailing community standard should be revised to address the acceptability of a specific prescription to meet that generic need.

d. Legislation should be passed requiring that private carriers broaden their definition of medical necessity and extend coverage to include technologies necessary to remove functional obstacles from the lives of people with disabilities.

e. Legislation should be enacted to ensure medical insurance coverage for the 29 months following disability layoff.

6. Rule 47, Department of Human Services, should be revised so that it encourages, rather than prevents technological advances.

   a. Rule 47 should be revised to recognize rehabilitation technological services for client evaluation, equipment selection, system design, client-equipment interface design, and training. Any organization with qualified staff legitimately engaged in the provision of rehabilitation technological services should also be made eligible for reimbursement.

   b. The Department of Human Services should be directed to devise efficient alternatives to the current prior authorization process (e.g. annual), postpayment audit including randomly selected case reviews) for institutions on the cutting edge of rehabilitation technology that are inordinately hampered by the current process.

7. The Medicaid Professional Services Advisory Committee should be expanded to include a subcommittee of persons familiar with new technological devices and services and who, in their daily work, set the standards for the care of patients who use new technologies. This subcommittee should:

   a. write a uniform, standardized definition of medical necessity that relates to the existence and extent of a generic medical need;

   b. make recommendations to the Department of Human Services about which technologies can be expected to yield reasonable benefit and value for given generic medical needs;

   c. regularly review prior authorization categories in order for the Deparment of Human Services to annually update prior authorization categories to reflect technological advances and progress.

8. A matching grant program should be enacted by the Legislature to encourage the use of public and private sector funds to support new program alternatives that promote the use of technologies by people with disabilities. The legislation should provide a mechanism for administering the program and should authorize state agencies to provide matching funds to agencies and programs which have successfully sought funds from private foundations for the development of such programs.

9. The Minnesota's Developmental Disabilities Council should study Pennsylvania's Assistive Device Loan Program and evaluate the advisability of proposing a similar program in Minnesota to provide technology appropriate to an individual's needs.

10. Grants, tax credits, and other incentives should be established and/or modified to encourage the development, modification and transfer of technologies to meet the needs of persons with disabilities by business and non-profit organizations in Minnesota and to assist consumers paying for needed devices and services. These could include:
    - **a.** a tax credit equal to a predetermined dollar amount of engineering time spent solving a problem related to technology applications for people with disabilities;
    - **b.** a recognition program to publicly honor companies and individuals for their efforts in developing new technologies or making technological adaptations/applications (e.g. a Governor's Award); and
    - **c.** a second medical cost threshold with costs exceeding that level applied directly as a tax credit that would compensate for the financial burden of severe, chronic impairments.

11. Assistance should be provided to companies to identify and document needs and existing technologies in order to help them design products usable by and accessible to people with disabilities. Examples include:
    - **a.** a "needed product list," functional limitations list, and design guidelines to help private industry understand existing needs; focus R & D efforts on the development of products needed by the population with disabilities;
    - **b.** strategies to guide/streamline the new product development process, including guidelines for hardware selection and development, software development, and how to conduct a product development project;
    - **c.** models for internal company procedures to coordinate product design and technology transfer and to encourage employees to develop products and technology applications for persons with disabilities.

12. A proposal should be developed for a Minnesota Center for Technology for People with Disabilities to coordinate, support and advance technology uses and applications through training, information dissemination, technical services, research and development, and technology transfer. The proposal should:

- **a.** outline the center's potential functions and programs;
- **b.** provide for start-up staff and a governing board structure;
- **c.** appropriate start-up funds and require a private sector match prior to the release of state dollars; and
- **d.** provide for the center to accept and expend donations to supplement the state appropriation and match.

Bibliography

Ablenet, Inc. (1985). *Case study.* Unpublished document, Minneapolis, MN: Author.

Bernard, R. (1985, September). Work stations for the disabled: Environment can be as important as hardware and software. *IEEE Technology and Society Magazine, IV*(3), 5-6.

Behney, C. D. (1986, February 20). *Technology and disability: Policy issues in the year 2005.* Paper presented at the Forum: Marketplace problems in communications technology for disabled people, Washington, DC.

Blaschke, C. L. (1986, February). Technology for special education. *THE JOURNAL.*

Bradley, B. (1985a, December 3). Handicapped get job boost via high tech. *The Christian Science Monitor.*

Bradley, B. (1985b, December 4). High tech offers a hand to the handicapped. *The Christian Science Monitor.*

Bradley, B. (1985c, December 4). Computer enables young man without a voice to talk about marriage, basketball. *The Christian Science Monitor,* p. 7.

Brannigan, M. (1985, December 6). Seat lift chairs for the infirm set off a medicare reimbursement controversy. *The Wall Street Journal.*

Brule, J. D. (1985, September). Computer assisted Braille translation. *IEEE Technology and Society Magazine, IV*(3), 3-4.

Communication Resource Center. (Date unknown). *Communication Resource Center helps give "voice" to nonvocal individuals* [Press release].

Dalrymple, G. F. (1985, September). My head controls my computer: Computer access with cerebral palsy. *IEEE Technology and Society Magazine, IV*(3), 7-10.

Enabling technology. (1985, October). [Special issue]. *Scientific Honeywueller, 6*(3), 19-30.

Holleman, J. J. (1986, February) Expanding opportunities: Disabled students and microcomputer instruction at Berkeley's Vista College. *THE JOURNAL,* pp. 68-71.

Inskip, L. (9186). Business executives look for ways to help the hard to employ. *Minneapolis Star and Tribune.*

Johnson, C. (1983). Changes help injured man build a new life. *Minneapolis Star and Tribune*

Johnson, P. (Date unknown). Making the computer compatible with you. [Source unknown].

Kissick, L. N., Jr. (Date unknown). *A real brief communication autobiography of me.* Unpublished manuscript.

Kulikowski, S., II. (1985, September). A programming environment for the nearly paralyzed. *IEEE Technology and Society Magazine, IV*(3). 11-13.

LaRocca, J., & Turem, J. (1978). *The application of technological developments to physically disabled people.* Washington, DC: The Urban Institute.

Lazzaro, J. J. (1986, March). Opening the workplace to the disabled. *High Technology,* pp. 54-56.

McGrory, E. (1986, April). The blind leading. *Corporate Report,* pp. 146-147.

Mineo, B. (1985, October). Technology for the future: A report from the Association for Retarded Citizens bioengineering program. *The Exceptional Parent,* pp. 11-12, 14-15.

Metropolitan Center for Independent Living & United Cerebral Palsy of Minnesota. (1984). *Used equipment marketplace: A strategy for cutting equipment costs.* St. Paul: Authors.

Minnesota Governor's Planning Council on Developmental Disabilities. (1985, January). *Developmental disabilities and public policy: A review for policymakers.* St. Paul: Department of Energy, Planning and Development.

Minnesota Governor's Planning Council on Developmental Disabilities (1984, March). *Toward a developmental disabilities policy agenda: Assuring futures of quality*. St. Paul: Minnesota State Planning Agency.

Minnesota Governor's Planning Council on Developmental Disabilities. (1984, April). *Policy analysis series paper no. 22: Improving the quality of life for people with disabilities: Potential uses of technology*. St. Paul: Minnesota State Planning Agency.

Minnesota State Council for the Handicapped, & Minnesota Committee for the Handicapped (1984). *A time to begin*. St. Paul: Authors.

Moore, J. (1985, October). Technology is not magic. *The Exceptional Parent*, pp. 41-42.

Office of Technology Assessment. (1982, May). *Technology and handicapped people* (OTA-H-179). Washington, DC: United States Congress.

O'Neil, H. (1985). *Creating opportunity: Reducing poverty through economic development*. Washington, DC: Council of State Planning Agencies.

Perpich, R. (1985, October). *Technology and innovation in living for persons with disabilities*. Presentation at Governor's Conference: Reaching toward new horizons, St. Paul, MN.

Phonic Ear, Inc. (1986, January 15). The many faces of funding. [Source unknown].

Rahimi, M.A. (1981, January). Intelligent prosthetic devices. *Computer*, p. 22.

Special report: Make way for computers that listen . . . and understand. (1986, February 15). *Breakthrough by Boardroom Reports, IV*(3), 10-13.

Sontag, S. (1985, August 24). For disabled, computers are creating new lives. *The New York Times*.

Starfire, B. (1985, October 4). Computers meet needs of handicapped. St. Paul Pioneer Press and Dispatch.

Teaching personal computers to listen. (1985, December 9). *Fortune*, p. 121.

Waldsmith, L. (1985, December). Disalbing attitudes. *Minnesota Business Journal*, pp. 41-45.

White, R. C., & Cormier, R. J. (1986, February). The Rehabilitation Project in Data Processing: A prototype demonstration project of university, state government, and industrial cooperation. *THE Journal*, pp. 72-76.

Withrow, F. B., Withrow, M.S., & Withrow, D. F. (1986, February). Technology and the handicapped. *THE Journal*, pp. 65-67.

Summary Statement

The next five to ten years are critical to the shape of our future. Action must be taken to share information, fund training, application and access efforts, and carry out ongoing research and development that expands on the promise of technology for people with disabilities. The costs of doing so will be far outweighed by savings in productivity, economic growth, human dignity and well-being.

We cannot afford to lose this opportunity to lead the nation in applying new technologies to enable persons with disabilities to pursue productive, skilled employment; discover their talents and gifts; enjoy social and recreational opportunities in a way not possible without technology. Minnesota's economy has prospered from a strong high technology industry, and one of the most outstanding medical service and research communities in the world. Our workplaces encourage the entrepreneurial spirit, a tradition of cooperation between business, government and the arts. We have a tradition of civic pride that is based in our shared concerns for each other.

Throughout the course of the Issue Team's discussions, the commitment of each team member to individuals with disabilities was clear. Each team member had a particular expertise. Yet, when the time came to formalize our recommendations, the focus always returned to the person with a disability.

While discussing possibilities, the team never lost sight of social, economic and political realities that exist today for policymakers, business people, service providers and persons with the disabilities.

Often the discussions would expand to include the "practical" problems that confronted them. The dialogue would go like this: "We developed an aparatus for Bob so he can reach things on the top shelf from his wheelchair. How do you market this to others?" Or "Mary came back to work after her injury and here's how we adapted her work station . . . " or "Paul can only use the index finger on one hand, but with the microcomputer he's able to communicate with his family." This sharing of experience and personal commitment helped form the recommendations in this report.

The same personal commitment was exhibited by team members in their attendance at meetings and their follow-through on project assignments. The skill with which the team was able to address the broad and complex issues involved in this task is commendable.

My special thanks to the Minnesota Department of Jobs and Training for loaning Ed Opheim who was staff consultant to the team; Colleen Wieck and Roger Strand from the Governor's Planning Council on Developmental Disabilities for their technical assistance and funding; to the employers of the team members for their commitment to the project; to Cyndy Crist and the editorial group for the hours spent on preparing the final report, and especially to each of the issue team members — your dedication is inspiring! It has been a privilege to work with you.

Rachel Wobschall

Rachel Wobschall, Chair
Issue Team on Technology
and Persons with Disabilities
May 1986

The following persons served on the Issue Team on Technology for Persons with Disabilities and jointly prepared this report:

Sandy Anderson
Metro Center for Independent Living

Gregg Asher
Mankato State University

Marty Carlson
Gillette Hospital

Linda Carroll
Office of the Senate Majority Leader

Cynthia L. Crist
Governor's Office of Science and Technology

Kim Fors
Midwestern Robotics

Ray Fulford
Courage Center

Budd Hagen
Closing the Gap

Delores Hagen
Closing the Gap

Greg Holey
Minnesota Education Computing Corporation

Charles Hunt
Honeywell

Ron Kaliszewski
State Planning Agency

Tom Kellenberger
Department of Human Services

William Niederloh
Division of Rehabilitation Services

Edwin Opheim
Division of Rehabilitation Services

Dr. Sharon K. Patten
HHH Institute of Public Affairs

Janet Rubenstein
United Cerebral Palsy of Minnesota

Cheryl Waite
Ablenet

Rachel Wobschall
Office of the Governor

Jim Stenswick, Governor's Office

EXECUTIVE SUMMARY

Technology for People with Disabilities

State of Minnesota
June, 1986

D I S ABILITIES

FINDINGS

While technological devices and workplace adaptations can be very expensive, companies are finding that these costs are often far outweighed by the cost of long term disability payments. In addition to savings in wages earned and lowered workers' compensation and unemployment compensation rates, new technological developments can also bring about significant cost savings by helping prevent the occurrence of disabling conditions; allowing people with disabilities to live in independent or semi-independent settings rather than in high cost institutions; and providing the education and training necessary to enhance the employability of people with disabilities.

A significant gap exists between the possibilities offered by technological devices and processes and the realities of their applications or uses. Some restrictions are purely monetary, resulting in part from the high cost of many technological devices or adaptations relative to functional limitations. Others result from a lack of adequate, available information about technologies for those who could benefit from such knowledge. Still others result from gaps in the process of research and development, that broad area of activity in which needs are identified and products and processes that can meet those needs are developed. All three of these areas must be addressed if disabled Minnesotans are going to be able to fully avail themselves of and benefit from appropriate uses of technology.

A. Information Dissemination. Four activities must occur in order for accurate information to be disseminated to appropriate individuals: collection, dissemination, practical application, and training. We find, however, that the following is true in Minnesota:

1. There is no systematic effort to gather information about existing technologies and their applications or to disseminate it. What collection and dissemination is taking place is happening sporadically and with no consistency or overall coordination;

2. There is no site at which people with disabilities and the professionals and concerned others associated with them can have access to equipment in order to assess potentially appropriate uses or applications; and

3. Assistance in selecting and using appropriate devices and processes is not available to all persons with disabilities nor are such services available throughout the state. It is provided only to some in isolated, though excellent, situations.

B. Funding. Financing technological devices and services is an essential prerequisite for their uses. However, current public and private policies and practices are not adequately meeting the funding needs of persons with disabilities, thereby inhibiting their ability to purchase needed devices and rehabilitation services. Specifically, the following problems exist:

1. State agency definitions of key terms, particularly "medical necessity" and "prevailing community standard," are unnecessarily restrictive and are therefore preventing or delaying full, appropriate uses of technology;

2. Public funding policies do not recognize rehabilitation engineering for conducting assessments needed to select appropriate equipment and provide training to ensure the full, proper, and safe use of that equipment, and the prior authorization procedure for payments is unnecessarily restrictive; and

3. The definitions of medical necessity used by private insurance carriers that insure the majority of families with children who are handicapped and adults with disabilities are even narrower and more restrictive than those used by public entities, and their policies, therefore, do not cover the technologies necessary to remove functional obstacles from the lives of people with disabilities.

C. Research and Development. Introducing new technologies into the lives of people with disabilities is a massive undertaking. Many variables must be considered such as: type and severity of disabling condition, range of specialized technology either currently being used or needing development as well as the systems and services needed for application. The federal government has a clear role in carrying out and supporting disability related research and development and setting national research priorities, but their distance from consumers and current funding limitations have diminished the effectiveness of efforts at this level. In many ways, states are in a more appropriate position to address the needs of people with disabilities. In Minnesota, there is at present no consistent effort to do so. Effective disability related research and development is not taking place in Minnesota because:

1. No effort is underway to identify and document existing technologies and the unmet needs of persons with disabilities.

2. There is no mechanism to disseminate such information to producers and consumers and to encourage ongoing dialogues between them; and

3. Specialized applications for disabled persons are often expensive, but no incentives exist to encourage companies or individuals to develop and/or transfer new and existing technologies and technology uses for that purpose.

RECOMMENDATIONS

Technology offers means to ameliorate the limitations posed by a variety of disabilities. Carefully guided action is required to ensure that appropriate devices and services are available to and accessible by Minnesotans with disabilities. The following recommendations provide the means to take such action and, given sufficient funding and staff support, could be implemented within a two-to-three-year time period.

1. An on-going Advisory Board on Technology for People with Disabilities should be established.

2. A mechanism should be established to gather information on existing technology for persons with disabilities and to dispense it through central collection site.

3. A statewide media campaign should be developed to heighten public awareness of available technology-based products and services and their implications for persons with disabilities.

4. A sequential strategy should be developed to provide technology-related training to professionals in special education, rehabilitation, county case management, and other areas of caregiving, as well as families.

5. Public agencies, private insurance carriers, and Health Maintenance Organizations should be required to expand their definitions of medical necessity, revise their definitions of prevailing community standard, and provide extended disability insurance coverage.

6. Rule 47 should be revised so that it encourages, rather than prevents technological advances.

7. The Medicaid Professional Services Advisory Committee should be expanded to include a subcommittee of persons familiar with new technological devices and services to advise the Department of Human Services on appropriate technology matters.

8. A matching grant program should be enacted by the Legislature to encourage the use of public and private sector funds to support new program alternatives that promote the use of technologies by people with disabilities.

9. Minnesota's Developmental Disabilities Council should study Pennsylvania's Assistive Device Loan Program and evaluate the advisability of proposing a similar program in Minnesota.

10. Grants, tax credits, and other incentives should be established and/or modified to encourage the development, modification, and transfer of technologies to meet the needs of disabled persons and to assist consumers paying for needed devices and services.

11. Assistance should be provided to companies to identify and document needs and existing technologies in order to help them design products usable by and accessible to people with disabilities.

INTRODUCTION

In recent years, there has been a tremendous acceleration in the rate of technological innovation, with new devices and processes being developed that can enhance the daily lives and activities of people with disabilities. An enormous range of technological devices is potentially available to help individuals function more fully in areas such as mobility, communication, and the negotiation and control of their environment. Technological advances are also applicable to educational and vocational programs. For persons with disabilities, the availability of assistive devices or technology-related services can mean the difference between employment or unemployment, independent or dependent living, and the ability or inability to participate in the normal, everyday affairs of a community. Action is needed to ensure that technological devices and services are available and accessible to people with disabilities.

DEFINITION AND INCIDENCE

A disability is anything that challenges the development or functioning of an individual, such as sensory, physical, mental, or emotional impairments. Accidents, disease, congenital defects, and aging are the primary causes of limitations to a person's ability to perform one or more important life functions. The limitations imposed by these conditions range from those easily overcome (e.g., wearing eyeglasses to improve visual acuity) to those for which compensation is more difficult or complicated (e.g., the mobility and routine functioning of a person who is quadriplegic).

According to United Nations estimates, more than 400 million people, or 10 percent of the world's population, are disabled. U.S. Census Bureau statistics indicate that there are about 35 million people in the United States who are disabled. In Minnesota, it has been estimated that 14.5 percent of all Minnesotans are limited in one or more functions of daily living as a result of a disability.

COSTS TO SOCIETY

The costs to society of failing to help persons with disabilities to live full productive lives are high. According to national estimates, between 50 and 80 percent of working-age people with disabilities are unemployed. The poverty level among persons with disabilities has increased to 70 percent of families whose heads of households are disabled and earning less than $10,000 per year, as compared to 60 percent in 1975. The resulting cost to society is estimated at $300 billion per year, or $25,000 to $35,000 in lost wages, lost economic growth, food stamps, and medical payments, as well as worker's compensation and unemployment insurance, for each of the 10 million unemployed people with disabilities in the U.S.

12. A proposal should be developed for a Minnesota Center for Technology for Disabled People that would coordinate, support, and advance technology uses and applications for people with disabilities through implementation and training, information dissemination, technical services, research and development, and technology transfer.

FUTURE IMPLICATIONS

Advanced technology is widely available in general, but its transfer to the special, long-term needs of persons with disabilities has been slow, sporadic, and uneven. At the same time, the population of persons with disabilities is increasing. We are at a point where dramatically effective, practical applications could become reality and be made widely available and accessible. The degree to which this will occur depends on the intensity and effective coordination of information dissemination, funding, and public and private sector research and development efforts.

Implementing the recommendations outlined in this report would require some state appropriations, but many of these actions would not require direct expenditures. Others would use state funds to leverage additional dollars from the private sector. A biennial appropriation of $500,000 could bring about the establishment of a Center for Technology for People with Disabilities whose staff could spearhead and coordinate many of the actions which we have recommended.

We cannot afford to pass up the opportunity to utilize technology to its fullest potential in order to help people with disabilities fully participate in our society. Minnesota's economy has prospered from a strong base of technology intensive firms, an enduring entrepreneurial spirit, a tradition of cooperation, and an abiding concern for our fellow citizens. These same strengths give us the ability to lead the nation in the application of new technologies to the needs of people with disabilities and to focus on the abilities, rather than the disabilities, of those with functional limitations.

The next five to ten years will be crucial to the shape of the future. Action must be taken in the areas of information sharing, funding, and research and development within a carefully conceived strategy that is fully supported with adequate human and financial resources. The costs of doing so will be far outweighed by savings in productivity, economic growth, and human dignity. We can afford to do no less.